

Volitional Non-adherence in Pediatric Asthma:  
Its Occurrence and Relation to Disease Severity and Self-Efficacy

By

Copyright 2007

Jade Andromeda Bender, B.A.

Submitted to the graduate degree program in Clinical Child Psychology and the Faculty of  
the Graduate School of the University of Kansas in partial fulfillment of Master's of Arts

---

Michael C. Roberts, Chairperson

---

Camille Randall, Committee Member

---

Bridget Biggs, Committee Member

Date defended: \_\_\_\_\_

The Thesis Committee for Jade A. Bender, B.A. certifies that this is the  
approved version of the following thesis

Volitional Non-adherence in Pediatric Asthma:  
Its Occurrence and Relation to Disease Severity and Self-Efficacy

---

Michael C. Roberts, Chairperson

---

Camille Randall, Committee Member

---

Bridget Biggs, Committee Member

Date approved: \_\_\_\_\_

## ABSTRACT

Jade A. Bender

Clinical Child Psychology Program

Departments of Applied Behavioral Science and Psychology, October 2007

University of Kansas

Recent adherence theories have diverged to include two subtypes of non-adherence: inadvertent (e.g., forgetting) and volitional. Volitional non-adherence focuses on deliberate changes that patients and families make to their prescribed medication regimens. The purpose of this study was to (a) describe the types of changes parents make to their child's asthma regimen and the motivating factors for those changes, and (b) explore potentially related medical and psychological factors. Findings indicated that approximately 80% of parents reported making purposeful changes to their child's asthma regimen and that the majority of these changes involved decreasing prescribed medications. Furthermore, the most commonly reported reasons for making changes to medications included a desire to reduce treatment burden, control symptom exacerbations, and improve quality of life. Lastly, findings indicated that parents who were volitionally non-adherent did not differ significantly with regard to perceived self-efficacy for asthma management and disease severity when compared to parents who reported being adherent. This study highlights the importance of considering and incorporating the family's view and overall treatment goals when prescribing treatment regimens.

## TABLE OF CONTENTS

I. Introduction .....	6
II. Method .....	11
III. Results .....	15
IV. Discussion .....	21
V. References .....	29
VI. Appendices .....	32

## LIST OF APPENDICES

Appendix A. Asthma Care Behaviors Questionnaire	..... 32
Appendix B. Asthma Management Self-Efficacy	..... 43
Appendix C. Functional Severity Index	..... 45
Appendix D. Patient Information Form	..... 48

## Volitional Non-adherence in Pediatric Asthma:

### Its Occurrence and Relation to Disease Severity and Self-Efficacy

With prevalence rates ranging from 5.7% to 11.9%, depending on the state, asthma impacts the lives of approximately 6.2 million children in the U.S. (American Lung Association (ALA), 2006; Center for Disease Control and Prevention (CDC), n.d.). Asthma is defined by wheezing episodes, shortness of breath, chest tightness, and/or coughing. Currently, there is no cure for childhood asthma; however, with proper disease control, children can live healthy, productive lives. Managing the disease involves avoiding triggers, such as allergens and irritants (e.g., smoke), and following a medication regimen. The regimen (i.e., asthma action plan) usually involves a combination of inhaled corticosteroids, or “controller” medicines that are taken daily to prevent symptoms, and bronchodilators, or “rescue” medicines that are taken during a symptom exacerbation (Schaffer, 2006).

Like other chronic diseases, non-adherence is a prevalent concern with asthma. In fact, researchers have found that only about 20-73% of prescribed asthma medication doses are taken (Cochrane, Bala, Downs, Mauskopf, & Ben-Joseph, 2000) and that the mean rate of non-adherence for asthma medications in children is around 48% of prescribed doses (McQuaid, Kopel, Klein, & Fritz, 2003). Negative outcomes associated with non-adherence in asthma include overutilization of medical services, sleep disturbance, decreased participation in physical activity, and death (Schaffer, 2006). Non-adherence to asthma medications is also responsible for 14 million missed days of school annually and is among the third ranking cause of hospitalizations of children under the age of 15 (ALA, 2006; CDC,

n.d.). The high rates and significant impact of non-adherence to pediatric asthma regimens underscore the importance of understanding its occurrence.

Generally speaking, adherence, as a concept, has consisted of the assumption that patients' behaviors regarding their medications, diets, and lifestyle changes, should conform to medical providers' recommendations (see Noble, 1998; Trostle, 2000 for a description of adherence theories). However, a recent paradigm shift involving a patient-centered perspective has led to new ways of thinking about what motivates patients' medical attitudes and behaviors. Bauman (2000) posited that there are, in fact, two types of non-adherence: inadvertent and volitional. While *inadvertent* non-adherence entails not following the providers' recommendations because of an unintentional oversight such as forgetting medications or not understanding treatment plans (e.g., Rand, 2005), *volitional* non-adherence involves reasoned or purposeful decision-making on the part of the patient not to follow the providers' recommendations (Adams, Dreyer, Dinakar, & Portnoy, 2004; Bauman, 2000). Thus, an example of volitional non-adherence would be when parents *decide* to decrease the amount of medication their child is taking each day because they do not like the side effects of the medication.

The concept of volitional non-adherence centers around two basic assumptions. First, it assumes that patients and their families have special expertise about the illness that complements the knowledge of medical professionals. Consequently, this assumption implies that the patient and his or her family should be included as an integral part of the medical decision-making team (e.g., Bauman, 2000; Korsch & Marcy, 2000). Second, volitional non-adherence assumes that part of the decision-making process for patients is

determining how to balance the burden of the disease with the burden of treatment. In other words, patients and their families may actively change their recommended treatment because the cost-benefit ratio for fully participating in treatment favors non-adherence (e.g., Bauman, 2000; George & Apter, 2001).

Currently, most of the literature on volitional non-adherence is largely theoretical. For instance, Bauman (2000) posited several possible risk factors for volitional non-adherence, including difficult medical regimens, patient skepticism about the efficacy of the treatment, and family financial concerns. However, only a few studies have examined why families intentionally alter their medication regimens and the implications of such medication changes. For instance, Deaton (1985) conducted a study on children with asthma and their parents and found that patient and family beliefs about compliance were associated with better outcomes (e.g., quality of life, illness control), whereas their degree of compliance was not. More specifically, parents expressed beliefs about having expertise that supplemented the provider's abilities and reported that changing the medication regimen was a viable option. Greaves, Hyland, Halpin, Blake, and Seamark (2005) further supported the idea that patients feel they have the right to change their medication regimen by finding that there are three self-reported patterns of medication use in adults with asthma. The "regular" pattern describes patients who primarily adhere to their treatment regimen. The "regular-but-less" pattern refers to patients who take their medications on schedule but in lower doses, and the "symptom-directed" pattern pertains to patients who change their medication regimen in response to variability in their symptoms. Greaves and colleagues also found that these patterns of adherence led to comparable numbers of unscheduled clinic visits and quality of



life in patients with mild to moderate asthma, suggesting that volitional non-adherence did not result in adverse outcomes. However, outcomes differed between patterns of adherence for patients with severe asthma, perhaps because non-adherence has the potential to lead to more serious health concerns. Taken together, findings by Deaton (1985) and Greaves et al. (2005) suggest that patients or parents make intentional changes to medications and that, in some cases, these changes are not associated with maladaptive outcomes.

Graves and colleagues (in press) added further insight into these changes by describing the types of changes parents of children with asthma make to their medications and the motivating factors for these changes. For instance, they noted that families tend to decrease their controller medications and increase their rescue medications. This corresponds with Modi and Quittner's (2006) findings that daily medicines, such as controllers, present greater numbers of treatment barriers than short term medications, such as rescue inhalers. Though volitional non-adherence per se was not assessed in this study, one might infer that more barriers could lead to planned decisions not to adhere to a regimen. Examples of barriers that Modi and Quittner identified and could potentially motivate volitional non-adherence include side effects (e.g., taste), time management, and child opposition.

While this research provides some initial insight into volitional non-adherence with pediatric asthma, many questions remain unanswered. For instance, little research has been conducted to describe the types of patients and families that are most likely to volitionally non-adhere to their medication regimen and elucidate the motivating factors for volitional non-adherence. Furthermore, little is understood about what psychological factors might be associated with volitional non-adherence (e.g., self-efficacy with regards to managing the

medical regimen). Such investigation should lead to a better understanding of how to intervene effectively with non-adherent families to promote optimal health outcomes.

As a result, this study has three aims. First, a newly developed measure of volitional non-adherence in parents of children with asthma will be used to obtain descriptive data with regard to the types of volitional changes parents make to their children's asthma medications and the possible reasons why they make these changes. Based on clinical experience and existing (but limited) research, it is hypothesized that parents will (a) more likely report increasing rescue medications and decreasing controller medications when making volitional changes; (b) most often endorse improving quality of life and alleviating symptom exacerbations as motivating factors for increasing medications; and (c) most often report a desire to reduce treatment burden, evaluate the child's need for medications, and decrease side effects as reasons for decreasing their child's medications.

The second aim is exploratory and examines whether parents who engage in volitional non-adherence differ significantly from parents who report adhering to their child's prescribed regimen with regard to parents' perceived self-efficacy in preventing and managing their child's asthma. This variable was chosen because it reflects parents' perception of their ability to identify symptoms accurately and then appropriately respond to exacerbations, as well as their perceived ability to manage their child's asthma and thereby prevent symptom flares. It is possible that parents who have a greater understanding of their child's asthma symptoms and are more confident about their abilities to manage the asthma will be more likely to alter their child's medication to meet their treatment goals.

Finally, the third aim of this study investigates whether parents who report volitional non-adherence endorse significantly more asthma symptoms and functional impairment for their child than parents who report adhering to their child's asthma regimen. Deaton (1985) suggested that despite being non-adherent, many families may still effectively manage their child's symptoms by following aspects of the prescribed medication regimen rather than the entire regimen. For instance, although controller medications are intended to be taken on a daily basis, Boushey, Sorkness, King, and Sullivan (2005) found that intermittent use of controller medications produced similar rates of symptom exacerbations as daily use in their sample of adult patients. Thus, it is possible that parents who endorse volitional non-adherence will report similar levels of symptom exacerbations and impairment for their children when contrasted with reports of adherent parents, based on the assumption that non-adherent families are altering their child's medication regimens in response to their child's treatment needs.

## Method

### *Participants*

Caregivers of children with asthma were recruited from two university-affiliated hospitals, one in the Midwest and the other in the southern United States. Caregivers were approached at the time of their child's routine appointment in an asthma clinic if they (a) had a child between the ages of 1 and 17 years with an established diagnosis of asthma; and (b) could speak English and had the requisite reading skills to complete a series of study-related questionnaires.

## *Measures*

The *Asthma Care Behaviors Questionnaire – Parent Version* (ACBQ; see Appendix A) is a 51 item measure that was designed to assess volitional non-adherence in parents of children with asthma. More specifically, the measure queries parents about what types of asthma and allergy medications their child has been prescribed and whether or not they have intentionally modified the ways in which their child took the medicine over the last three months (7 items). The ACBQ also uses a true/false response format to ask parents why they increased and/or decreased their child's medications (38 items), and how they generally went about making those changes (6 items).

A panel of four asthma, allergy, and psychology professionals devised the ACBQ. Its development began with a review of the literature on volitional non-adherence and panel discussion of related constructs. Eventually, its content (type of volitional non-adherence, motivating factors underlying it, and general approach) was agreed on and three corresponding sections were created. For the first section, all classes of current asthma and allergy medications were identified and separated by mode of delivery (e.g., nebulizer versus metered dose inhaler) because the panel agreed that families might modify one type of medication and/or mode of delivery, but not another. For the second section, the panel used reviews of adherence barriers literature and clinical experience to generate various reasons that could potentially motivate families to increase or decrease medications beyond physician instructions. For the final section of the ACBQ, items were generated with regard to overall approach to the family's decision-making process. Finally, questionnaire instructions were fine-tuned to be certain that parents were recording responses reflecting *volitional* non-

adherence instead of inadvertent non-adherence and/or changes that were stipulated in the child's asthma action plan.

The panel then solicited input from other asthma and psychology colleagues on the structure and content of the first draft of the questionnaire (version 1.0). After making suggested revisions, the ACBQ (version 2.0) was administered to a pilot group of 10 families, followed by individual, semi-structured interviews designed to solicit specific feedback with regard to wording of questions, potential social desirability in responding, and ease of measure completion. Revisions were made in response to their feedback, leading to the third version (3.0) of the ACBQ which was used in this study. Because this is the initial study using the ACBQ, no psychometric properties can be reported.

*Asthma Management Self-Efficacy (AMSE;* Bursch, Schwankovsky, Gilbert, & Zeiger, 1999). The AMSE (see Appendix B) is a 13 item measure that uses a 6-point Likert scale to gauge parents' beliefs about their abilities to prevent asthma attacks (e.g., correctly administer medications, get child to doctor's appointment) and manage asthma attacks (e.g., control symptoms, decide when to go to the emergency room). The scale has demonstrated good internal consistency ( $\alpha = .87$ ) and construct validity. Higher total score and subscale scores suggest greater perceived self-efficacy.

*Functional Severity Index (FSI;* Fritz, McQuaid, Spirito, & Klein, 1996). The FSI (see Appendix C) is a 13-item, parent-report measure of children's asthma symptoms and functional impairment (e.g., nighttime awakening, school absences). More specifically, the first six items of the scale assesses the frequency of episodes, frequency of symptoms between episodes, intensity of impairment during an episode, and intensity of impairment

between episodes, and the remainder of the scale assesses health care utilization and extreme asthma events. The FSI score was calculated by computing a mean for the first six items (Rosier, Bishop, Nolan, Robertson, Carlin, & Phelan, 1994). Higher FSI scores suggest increased symptoms and impairment. Internal consistency for the first six items of the current sample was calculated at  $\alpha = .86$ . Previous studies have reported full scale reliability estimates around  $\alpha = .80$  (e.g., McQuaid et al., 2003).

*Patient Information Form (PIF).* The PIF (see Appendix D) was designed specifically for this study to gather demographic and medical information about the child and his or her family. These data were used to describe the participant sample.

### *Procedure*

During the clinic appointment, a research assistant approached eligible participants, explained the purpose of the study, and offered them the opportunity to participate. Written informed consent, in accordance with hospital policy, was obtained prior to enrollment. Instructions for each questionnaire were explained in detail and caregivers completed the questionnaires independently unless they expressed a need for further clarification and/or reading assistance. The researcher also emphasized the confidential nature of the parent's response and indicated that most families do not follow their regimen perfectly in an effort to reduce social desirability in responding. Parents completed the questionnaires in random order. Once parents completed the forms, they were compensated for their time with a \$5 gift certificate.

## Results

### *Participants*

One hundred and thirty five primary caregivers of children (1-17 years old;  $M = 7.86$ ;  $SD = 4.15$ ) with a diagnosis of asthma (average time since diagnosis = 5.24 years;  $SD = 3.62$ ) participated in the study during a regularly scheduled visit to an allergy and asthma clinic. Approximately 62% of the children were male, with 56.4% identifying as Caucasian, 30.8% as African-American, 6.8% as Hispanic American, 4.5% as Other Ethnicity, and 1.5% as Asian American. Most children had a diagnosis of mild or moderate persistent asthma (34.2% and 40.5%, respectively).

Caregivers ranged from 19 to 63 years of age ( $M = 35.46$ ;  $SD = 7.62$ ) with 85.7% of caregivers identifying themselves as mothers, 10.5% as fathers, and 3.8% as other (e.g., grandparent). Approximately half of the sample came from families with both biological parents living in the home, 26.5% from single parent homes, 12.9% from blended families (e.g., step-parent), and 6.8% reported other family structures (i.e., living with a grandparent). Median education level for mothers and fathers was vocational training and/or some college education, and the average annual income was between 30,000 and 39,999 dollars indicating that these families were in the lower to middle socioeconomic range.

### *Preliminary Statistical Analyses*

For the first section of the ACBQ, item responses were collapsed into “increase medication” (increase dose, increase schedule), “decrease medication” (decrease dose, decrease schedule, stop medication altogether), or “no change” for each class of medication.

Although factor analysis would be the preferred method for deriving summary variables for the second section of the ACBQ (i.e., items tapping motivational factors for increasing or decreasing medications), sample size was not sufficient to produce a reliable factor structure. Consequently, a combination of expert ratings, item-to-total correlation analyses, and clinical judgment was employed to create summary variables for those 38 items. Specifically, two steps were taken. First, experts were provided with a complete list of items and a set of categories (see Table 1) in which to place each item, with the possibility of writing in their own category as well. These summary categories were created by reviewing research on the risk factors for and barriers to adherence (e.g., Bauman, 2000).

Table 1: *Expert Category Definitions*

Category	Description
Anxiety	Medications were increased to reduce anxiety.
Symptom Control	Medications were increased to prevent or control asthma exacerbations.
Quality of Life (QoL)	Medications were increased to improve the child's quality of life (e.g., daily functioning).
Perceived Need	Medications were decreased because the family did <u>not</u> perceive a need for the medications prescribed or had a desire to determine whether or not there was a true physical need for the medication.
Treatment Burden	Medications were decreased because the family wanted to reduce the burden that the treatment imposed.
Side Effects	Medications were decreased to reduce or avoid medication side effects.
Financial Concerns	Medications were decreased due to financial concerns or desires.
Mistrust	Medications were decreased because the family mistrusted the prescribed medications.
Child	Medications were decreased in accordance with child preferences or because of child opposition.

Expert raters consisted of a total of seven healthcare professionals (i.e., asthma educator, allergist, pediatric psychologist) from different regions of the U.S. An item was retained if at least 75% of the raters agreed on its category placement (DeVellis, 2003; Logan, Zelikovsky, Labay, & Spergel, 2003; see Tables 2-3 for deleted items).



Table 2: Deleted Reasons for Increasing Medications

Item	Highest Percent of Agreement	Category
My child wanted to avoid taking antibiotics for his chest symptoms	62.5	Symptom Control
We wanted to have better control over my child's asthma	62.5	Symptom Control
My child couldn't sleep through the night without asthma symptoms.	50	Symptom C & QoL
My child wanted to not use his rescue inhaler so much.	62.5	QoL

Table 3: Deleted Reasons for Decreasing Medications

Item	Highest Percent of Agreement	Category
The amount of medicine the doctor told my child to take was too much.	50	Need
The medicine did not seem to be working.	57.1	Need
We did not agree with the doctor's diagnosis of asthma or allergies.	50	Need/Mistrust
Taking too much medicine was bad for my child.	50	Side Effect
We were worried the medications would not work after some time if our child took them too long.	37.5	Side Effect/Mistrust
We were worried that our child would become addicted or dependent on the medications.	62.5	Side Effect
We ran out of the medicine before we could get more.	50	Burden

Second, item-to-total correlations were conducted for each item retained by the expert ratings. Specifically, these correlations were assessed within each cluster of items rated as belonging to a particular category with more than one item. Items with a negative item-to-total correlation were examined and deleted from the measure if it was determined that they were written in a relatively unclear manner (see Table 4).

Table 4: Deleted Items Based on Item-to-Total Correlation and Wording

Item	Category
We did not want to worry about our child's asthma so we changed the medicine routine.	Anxiety
We wanted to find out what would happen to our child's asthma if he stopped taking a medication.	Need
Life was too busy and our child forgot the medications too often to bother taking it at all anymore.	Burden

Thus, the following items were retained to create the ACBQ categories that were used in the primary analyses (see Tables 5-6).

Table 5: *Expert Category Ratings of Reasons for Increasing Medications*

Category	Item	Percent of Agreement	Item-Total Correlation
Reduce Anxiety	We did not want to worry as much about our child's asthma so we changed the medicine routine.	100	N/A
Symptom Exacerbations	The amount of medication the doctor told my child to take was too little.	87.5	.280
	My child's asthma seemed to flare up with every cold or virus.	100	.333
	My child was becoming wheezy during normal/daily physical activity (e.g., walking).	75	.326
	My child's allergies seemed to be triggering my child's asthma.	100	.586
Quality of Life	My child's asthma was getting in the way of being able to exercise or play sports.	100	.355
	My child was missing too many school days because of his asthma.	87.5	.211
	We were tired of our child going to the emergency room or staying at the hospital because of his asthma.	75	.442

Table 6: *Expert Category Ratings of Reasons for Decreasing Medications*

Category	Item	Percent of Agreement	Item-Total Correlation
Need for Medications	My child's asthma got better.	100	N/A
Treatment Burden	My child was taking too many different medicines.	87.5	.517
	Carrying around the asthma medication supplies was too much hassle.	100	.646
	We did not like the way (e.g., spacer, inhaler) our child had to take the medications.	75	.159
	It was too hard to keep track of all my child's medications.	100	.545
	We wanted to make our medicine routine easier to follow or remember.	100	.517
	Taking medications got in the way of our family's daily life too much.	100	.585
Side Effects	The medicine made my child feel or act differently.	87.5	.371
	We wanted to get rid of the side effects from the medicine.	100	.371

Continues on next page.

Financial Concerns	The medicines cost too much money.	100	.273
	We wanted to make the medications last longer so we wouldn't have to buy as much.	100	.273
Mistrust of Medications	We wanted our child to use home remedies or other things that were not medicine.	100	N/A
Child's Preferences	My child got upset or threw tantrums and did not want to take the medicine.	100	.111
	My child complained that the medicine tasted bad.	87.5	.246
	My child did not want to take medications during an activity (e.g., sleepovers, sports).	100	.281
	My child did not want his friends to know that he had to take asthma medications.	100	.176

### *Primary Analyses*

*Aim 1:* The first aim of this study was to use the ACBQ to report descriptive data regarding the types of changes parents make to their children's medications and what motivates those changes. Frequency analyses determined that 80.5% of the parents in this sample reported intentionally altering their child's medications. More specifically, parents most often reported making changes to their child's rescue medications such that 21.3% of the sample reported increasing their child's rescue medications and 69% reported decreasing them. It was also more common for parents to decrease any type of their child's medications (79.4%) than to increase any medication (25.6%). Thus, the descriptive data mirror previous research (e.g., Greaves et al., 2005) by suggesting that the majority of families are volitionally non-adherent.

In addition to describing the types of changes parents of children with asthma make, it was further hypothesized that parents would be more likely to report increasing rescue medications and decreasing controller medications than the reverse. Considering the majority

of families reported decreasing medications regardless of the type, this hypothesis was not supported. It is possible that this finding contradicts previous research (e.g., Graves et al., in press; Modi & Quittner, 2006) because parents who are volitionally non-adherent may feel that daily medicines and short term medications, which still need to be on hand to be administered at times of need, pose comparable treatment barriers.

Another descriptive hypothesis in this study speculated that parents would most often endorse motivating factors that improve their child's quality of life and alleviate symptom exacerbations when increasing their child's medications. According to frequency analyses conducted on the expert category variables, 85.7% of parents who increased their child's medications endorsed symptom exacerbation as a motivating factor. Furthermore, 73.7% endorsed quality of life issues and 25.9% endorsed a desire to reduce anxiety. Thus, the hypothesis regarding motivating factors for increasing medications was supported.

It was also hypothesized that parents would endorse a desire to reduce treatment burden, evaluate the child's need for medications, and decrease side effects as the most prevalent reasons for decreasing their child's medications. In accordance with this hypothesis, the two most commonly reported reasons for decreasing medications were evaluating the child's need for medications (59.2%) and attempting to reduce treatment burden (42.3%). However, the third most common motivating factor for decreasing medications was that the child expressed a preference for and/or opposition to aspects of the medication regimen (36.5%). Consequently, these results suggest that for both increasing and decreasing medications, parents are considering not only the child's symptoms, but also how the medical regimen affects the child and the family as a whole.

*Aim 2:* The second aim of this study was to examine whether parents who report volitional non-adherence significantly differ with regard to perceived self-efficacy in asthma prevention and management when compared to those parents who report adhering to their child's regimen. Three analyses of covariance (ANCOVA) were conducted with adherent versus volitionally non-adherent entered as the independent variable, the AMSE subscale scores and total score entered as the dependent variables (each in a separate ANCOVA), and time since diagnosis entered as a covariate. Results suggested that neither attack prevention ( $F_{2,109} = .299, ns$ ), attack management ( $F_{2,109} = .630, ns$ ), nor overall perceived asthma self-efficacy ( $F_{2,109} = 1.461, ns$ ) discriminated between those parents who chose to alter their child's prescribed medications and those who did not.

*Aim 3:* An independent samples t-test was used to determine whether parents reporting non-adherence and those reporting adherence differed significantly with regard to their child's functional severity. Results of this analysis were not significant ( $t_{123} = -.247, ns$ ), suggesting that the hypothesis that the two groups of parents would not differ significantly was supported.

## Discussion

The primary purpose of this study was to examine the presence of and motivating factors for volitional non-adherence in parents of children with asthma. According to the results, most of the parents in this sample reported *intentionally* changing their child's medications. In fact, approximately 80% of parents reported decreasing their child's medications. These findings add to the previous literature on non-adherence to asthma medication regimens by underscoring the high prevalence of non-adherence. In fact, these

self-reported rates of non-adherence are even higher than those reported by researchers who have not distinguished between volitional and inadvertent non-adherence (e.g., Cochrane et al., 2000; McQuaid et al., 2003). It is possible that focusing on volitional rather than inadvertent non-adherence may be perceived as less judgmental by patients, and normalizing non-adherence during the data collection process may have led to fewer demand characteristics. Yet, rates of volitional non-adherence in the current study are also somewhat higher than those found by Greaves et al. (2005). Thus, differences in measurement specificity may have also played a role in the discrepancy between current results and those from past research. For instance, Greaves and colleagues asked generalized questions about patterns of asthma medication use (e.g., do you take your medication regularly but less than recommended) and focused solely on controller medications. In contrast, the first section of ACBQ details various ways (e.g., increase dose, increase frequency) in which a parent can alter each type of their child's prescribed medicine which might in turn spark their memory for changes they may have otherwise not considered. Despite differing rates of non-adherence, this study augments the existing literature by suggesting that non-adherence is more than simply forgetting to take medications or not understanding the medical regimen. Instead, the findings imply that many parents are in fact making reasoned decisions to change their child's asthma medications and may even be deciding to face the possible risks associated with non-adherence because the benefits of non-adherence are perceived to be greater.

The reasons why parents are choosing to be volitionally non-adherent seem to center around the impact of the child's asthma symptoms on the child and family's life. For

instance, parents reported that controlling symptom exacerbations and improving quality of life were the most common reasons for *increasing* their child's medications, and that evaluating the actual need for asthma medications, reducing treatment burden, and acquiescing to child preferences were the most common reasons for *decreasing* medications. It is not surprising that these factors were the most frequently endorsed reasons for engaging in volitional non-adherence as they have often been endorsed as barriers to treatment in general. For instance, Modi and Quittner (2006) found that the most commonly reported barriers to asthma treatment included time management issues, side effects, and oppositional child behaviors. These findings also lend support to Bauman's (2000) theory that factors specifically related to volitional, and not inadvertent, non-adherence would include the burden of the medical regimen, skepticism about the efficacy of treatment, and issues regarding medication side effects.

This correspondence between motivating factors for volitional non-adherence and barriers to adherence implies a need for better provider-patient communication. For instance, Noble (1998) recommended that health providers preface conversations with the expectation of non-adherence so that parents do not feel judged and are more open to discussion. Such open communication could in turn allow providers to better incorporate the family's concerns about barriers to treatment and address the factors that motivate them to be non-adherent. Simple changes such as altering the medication regimen to prescribe controllers once a day instead of twice a day may sufficiently address parents' concerns about treatment burden and negate poor adherence outcomes. Furthermore, if providers gain an understanding of what idiosyncratic factors motivate families not to follow their child's asthma regimen, they may

also be able to determine whether or not a family's specific reasons for non-adherence are appropriate (Greaves et al., 2005). For instance, skepticism about the efficacy of the medications or belief that a child has outgrown the illness may be inaccurate and indicate a need for educational interventions. Indeed, if healthcare providers do not regularly address such motivating factors in their appointments with families, family adherence will likely not be optimized.

While these results have provided some initial insight into the occurrence of volitional non-adherence, the exploratory findings regarding the role of parents' perceived asthma self-efficacy in adherence were contrary to what was predicted. It is possible that parents who are adherent report high perceived asthma self-efficacy because they are following their providers' recommendations and experiencing optimal health outcomes. Similarly, parents who are endorsing volitional non-adherence may report comparable levels of self-efficacy because other variables that may play a role in the relationship between non-adherence and self-efficacy are also promoting good health outcomes. For instance, patient knowledge and changing expectations of patient roles may factor into parents' decisions not to adhere (Korsch & Marcy, 2000). Indeed, the increasing availability of medical resources (e.g., via the internet) gives parents greater access to answers about questions they might have about how to change their child's regimens on their own. Furthermore, asthma action plans empower parents to engage in at least some decision-making by promoting symptom-based interventions. Thus, while parents who are adherent may have children with good symptom control, parents who are non-adherent may also have children who experience good



symptom control because they are using available resources to make educated decisions about how to change their child's asthma regimen.

As findings regarding self-efficacy suggest, parents who endorse volitional non-adherence and parents who report being adherent to their child's asthma regimen may not be so different. And in fact, the final aim of the study suggested that these two types of parents reported similar levels of asthma symptoms and functional impairment in their children. This may imply that parents who are volitionally non-adherent are still meeting their child's basic needs by administering enough medication to sustain good health outcomes. This lends support to the idea that there may in fact be an adequate level of adherence (Deaton, 1985) and that adjusting regimens to determine that adequate level of use (e.g., prescribing intermittent instead of daily controller medications as suggested by Boushey et al., 2005) should be considered in the future. In fact, this result is promising in that it suggests that there may be more flexibility than previously thought for provider's to address treatment barriers because parents are already demonstrating that making some changes to the asthma medication regimen is not necessarily maladaptive. Thus, parents could be educating providers on various ways to prescribe medications by sharing their personal expertise with their providers, and providers could educate parents on which changes have the greatest research support.

It should be noted, however, that this study utilized only parent-report. As a result, it is unclear if a difference in health outcomes would occur between volitionally non-adherent parents and adherent parents if the variables were derived from some other source (e.g., health care utilization data from chart review). Despite the argument that parents who are

volitionally non-adherent and parents who are adherent may be more similar than anticipated; other factors may still play a role in distinguishing families who engage in volitional non-adherence. Thus, future researchers should consider what other psychological, environmental, and medical factors (e.g., quality of life, access to educational resources) may characterize volitionally non-adherent families.

### *Limitations*

This study had a few limitations. First, because the overall project continues to gather more participants, the sample size for this preliminary analysis was insufficient to perform the appropriate psychometric analyses (i.e., factor analysis for a portion of its items) on the ACBQ and the results are primarily descriptive in nature. Thus, it is important to remain cautious when interpreting the results (particularly those from the summary variables for motivating factors) and potential implications of this study. It should be noted, however, that the sample was large enough to provide sufficient power for the statistical analyses conducted and reported here. A second limitation is that the representativeness of the sample may have been compromised because the sample was recruited from specialty asthma clinics which often see children with more poorly controlled asthma than primary care physicians. In other words, these families may be more non-adherent than the average asthma population, which could be reflected in the elevated rates of non-adherence. Third, the ACBQ is still under development. For instance, this version of the ACBQ only gave parents the option to identify their behaviors as adherent or *volitionally* non-adherent. Therefore, because families who engaged in *inadvertent* non-adherence could be included in either of these groups, the two groups of parents may be more similar than anticipated making it difficult to detect

significant differences between them. In addition to adding the option to indicate inadvertent non-adherence to future versions of the measure, the format continues to be reconsidered as many families have expressed difficulties completing the measure independently.

Consequently, a more streamlined version of the questionnaire or a semi-structured interview format may be more helpful. Changes that have already been incorporated into the attached edition of the ACBQ (see Appendix A) include adding pictures to help families distinguish which types of medications are being asked about, adding arrows to indicate which questions adherent parents can skip, and deleting confusing items in the section that queried about methods of making changes to medications. Despite these changes, the question of specificity versus generality in item content remains. For instance, simply knowing that a parent decreased their child's controller medication, and not that they decreased it by frequency instead of dose, may be sufficient.

#### *Future Directions and Implications*

Despite these limitations, this study sets the groundwork for future research on adherence theories by beginning to characterize volitional non-adherence in a sample of parents of children with asthma. As researchers' understanding of this concept improves, examining the psychological and health outcomes associated with differing levels and types of volitional non-adherence would be beneficial. For instance, determining whether there is a certain level at which non-adherence becomes maladaptive (Deaton, 1985), gaining greater insight into how to discriminate between inadvertent and volitional non-adherence (Bauman, 2000), and improving health care professionals' understanding of the health outcomes associated with *increasing* medications could inform clinical interventions. Interventions that

also encourage non-judgmental doctor-patient communication by taking into account patients' views and expertise could lead to improved adherence to prescribed treatment regimens (Korsch & Marcy, 2000; Noble, 1998). Moreover, encouraging open provider-patient discussions when volitional non-adherence is recognized may lead to improved adherence outcomes because specific barriers to treatment can be addressed. While there are many possible implications for future research and interventions, the immediate implication of this study is our understanding that many parents of children with asthma are not sitting passively and waiting to be told what to do to manage their child's illness. Thus, instead of presuming that parents will conform to the providers' recommendations, providers should take advantage of the personal expertise and advocacy that parents are demonstrating by querying and considering families' views when creating treatment regimens.

## References

- Adams, C., Dreyer, M., Dinakar, C., & Portnoy, J. (2004). Pediatric asthma: A look at adherence from the patient and family perspective. *Current Allergy and Asthma Reports, 4*, 425-432.
- American Lung Association. (2006). Asthma and children fact sheet. Retrieved June 7, 2007, from <http://www.lungusa.org/site/pp.asp?c=dvLUK9O0E&b=44352>
- Bauman, L. (2000). A patient-centered approach to adherence: Risks for nonadherence. In D. Drotar (Ed.), *Promoting adherence to medical treatment in chronic childhood illness: Concepts, methods, and interventions* (pp. 71-93). Mahwah, NJ: Lawrence Erlbaum Associates.
- Boushey, H., Sorkness, C., King, T., & Sullivan, S. (2005). Daily versus as-needed corticosteroids for mild persistent asthma. *The New England Journal of Medicine, 352*, 1519-1531.
- Bursch, B., Schwankovsky, L., Gilbert, J., & Zeiger, R. (1999). Construction and validation of four childhood asthma self-management scales: Parent barriers, child and parent self-efficacy, and parent belief in treatment efficacy. *Journal of Asthma, 36*, 115-128.
- Center for Disease Control and Prevention. (n.d.). Asthma and allergies. Retrieved June 7, 2007, from <http://www.cdc.gov/health/asthma.htm>
- Cochrane, M., Bala, M., Downs, K., Mauskopf, J., & Ben-Joseph, R. (2000). Inhaled corticosteroids for asthma therapy: Patient compliance, devices, and inhalation technique. *CHEST, 117*, 542-550.

Deaton, A. (1985). Adaptive noncompliance in pediatric asthma: The parent as expert.

*Journal of Pediatric Psychology, 10*, 1-14.

DeVellis, R. (2003). *Scale development: Theory and applications*. London: Sage Publications.

Fritz, G., McQuaid, E., Spirito, A., & Klein, R. (1996). Symptom perception in pediatric asthma: Relationship to functional morbidity and psychological factors. *Journal of the American Academy of Child and Adolescent Psychiatry, 35*, 1033-1041.

George, M., & Apter, A. (2001). Improving adherence to asthma medications. *Clinical Pulmonary Medicine, 8*, 257-264.

Graves, M., Adams, C., Bender, J., Simon, S., & Portnoy, J. (in press). Volitional non-adherence in pediatric asthma: Parent report of motivating factors. *Current Allergy and Asthma Reports*.

Greaves, C., Hyland, M., Halpin, D., Blake, S., & Seamark, D. (2005). Patterns of corticosteroid medication use: Non-adherence can be effective in milder asthma. *Primary Care Respiratory Journal, 14*, 99-105.

Korsch, B., & Marcy, S. (2000). Pediatric compliance from a patient and family perspective. In D. Drotar (Ed.), *Promoting adherence to medical treatment in chronic childhood illness: Concepts, methods, and interventions* (pp. 57-65). Mahwah, NJ: Lawrence Erlbaum Associates.

Logan, D., Zelikovsky, N., Labay, L., & Spergel, J. (2003). The Illness Management Survey: Identifying adolescents' perceptions of barriers to adherence. *Journal of Pediatric Psychology, 28*, 383-392.

- McQuaid, E., Kopel, S., Klein, R., & Fritz, G. (2003). Medication adherence in pediatric asthma: Reasoning, responsibility, and behavior. *Journal of Pediatric Psychology*, 28, 323-333.
- Modi, A., & Quittner, A. (2006). Barriers to treatment adherence for children with cystic fibrosis and asthma: What gets in the way? *Journal of Pediatric Psychology*, 31, 846-858.
- Noble, L. (1998). Doctor-patient communication and adherence to treatment. In L. Myers & K. Midence (Eds.), *Adherence to treatment in medical conditions* (pp. 51-82). Amsterdam: Harwood Academic Publishers.
- Rand, C. (2005). Non-adherence with asthma therapy: More than just forgetting. *Journal of Pediatrics*, 146, 157-159.
- Rosier, M., Bishop, J., Nolan, T., Robertson, C., Carlin, J., & Phelan, P. (1994). Measurement of functional severity of asthma in children. *American Journal of Respiratory and Critical Care Medicine*, 149, 1434-1441.
- Schaffer, S. (2006). Adherence challenges in asthma treatment. In W. O'Donohue & E. Levensky (Eds.), *Promoting treatment adherence: A practical handbook for mental health providers* (pp. 217-233). Thousand Oaks, CA: Sage Publications.
- Trostle, J. (2000). The ideology of adherence: An anthropological and historical perspective. In D. Drotar (Ed.), *Promoting adherence to medical treatment in chronic childhood illness: Concepts, methods, and interventions* (pp. 37-55). Mahwah, NJ: Lawrence Erlbaum Associates.

## Appendix A. Asthma Care Behaviors Questionnaire (ACBQ)



---

## Changing Our Child's Asthma Medicine Routine

---

### PART 1: INTRODUCTION

Many families make changes to their child's asthma and/or allergy medicine routine to find out what works best for their child's asthma and their family's routines.

In fact, families may change or adjust the **AMOUNT** of asthma medicine that their child takes or how **OFTEN** their child takes medicine in a way that is different from what the doctor said.

These changes in taking medicine are **NOT** the same as:

- **Changes stated in a child's asthma action plan** (e.g., to add a new medicine or increase the amount of a medicine if asthma problems occur).
- **Changes that come from just forgetting to take a medicine from time to time.**

Rather, these changes are **ON PURPOSE** or are **PLANNED**.

Families might make these changes in order:

- To get new information about their child's asthma (e.g., how the adjustment changes symptoms)
- To reach different treatment goals for their child's asthma (e.g., make asthma control better, cut number of medicines child takes, make medicine routine simpler or easier).

---

Some EXAMPLES are:

- **INCREASE the AMOUNT taken in each dose**
  - If your doctor told your child to take 2 puffs each time, he takes 3 puffs instead.
  - If your doctor told your child to take 1 pill each time, he takes 2 pills each time.
- **INCREASE how OFTEN (# of doses)**
  - If your doctor told your child to take a medicine at bedtime, he takes it at bedtime AND in the morning.
- **DECREASE the AMOUNT taken in each dose**
  - If your doctor told your child to take 2 tsp each time, he takes only 1 tsp.
  - If your doctor told your child to take 2 puffs each time, he takes only 1 puff.
- **DECREASE how OFTEN (# of doses)**
  - If your doctor told your child to take a medicine 2 times a day, he takes it only at bedtime.
- **STOP taking a medication altogether**

---

For each asthma and allergy medication, you will be asked to mark if you and your child have changed the **AMOUNT** (# of puffs, pills, teaspoonfuls per dose) of medicine your child has taken each time and/or changed how **OFTEN** (# of times during the day) he has taken that medicine over the **PAST 3 MONTHS**.

Again, you should **ONLY** mark changes that are:

- **DIFFERENT** than what your doctor told your child to take, and
- **DIFFERENT** than those medicine changes that your child's asthma action plan says, and
- **NOT** just changes that come from forgetting medicine from time to time.

Mark all changes that apply. More than one answer can be marked for each medicine, if it is true for your family. **YOUR ANSWERS WILL NOT BE SHARED WITH YOUR CHILD'S DOCTOR OR MEDICAL TEAM.**

---

## **PART 2: PRACTICE ITEM**

Before moving on to your child's allergy and asthma medicines, please mark answer(s) for the following EXAMPLE, so that we know you understand how to fill out this section of the questionnaire.

**A boy's doctor told him to take 2 puffs of his inhaler in the morning and 2 puffs at night (twice a day). Two months ago, this boy's family decided that he should only take 2 puffs at night. He did this for a few weeks, but then stopped using his inhaler altogether ever since then.**

- ☐ He took *MORE* puffs than the doctor said when he took it.
- ☐ He used the inhaler *MORE* times (more doses) than the doctor said during the day.
- ☐ He took *FEWER* puffs than the doctor said when he took it.
- ☐ He skipped doses (e.g., morning, bedtime, skipped a whole day).
- ☐ He stopped taking the medicine altogether.
- ☐ He did not change this medication at all. He took it like the doctor said.



1. **Asthma Controller Inhaler** (inhaled corticosteroid) –  
like Flovent, Advair, Pulmicort, QVar

Did the doctor ask your child to take this medicine?

YES ☐ (answer below)

NO ☐ (skip to #2)



How did you change this medication in the past 3 months?

- ☐ My child took *MORE* puffs when he took it.
- ☐ My child used the inhaler *MORE* times (more doses) during the day.
- ☐ My child took *FEWER* puffs when he took it.
- ☐ My child skipped doses (e.g., morning, bedtime, skipped a whole day).
- ☐ My child stopped taking the medicine altogether.
- ☐ My child did not change this medication at all. He took it like the doctor said.

2. **Asthma Controller Nebulizer** (corticosteroid breathing treatment) – like Flovent,  
Advair, Pulmicort, QVar

Did the doctor ask your child to take this medicine?

YES ☐ (answer below)

NO ☐ (skip to #3)



How did you change this medication in the past 3 months?

- ☐ My child took *MORE MEDICINE* during a nebulizer treatment.
- ☐ My child used the nebulizer *MORE* times during the day.
- ☐ My child took *LESS MEDICINE* during a nebulizer treatment.
- ☐ My child skipped nebulizer treatments (e.g., morning, bedtime, skipped a whole day).
- ☐ My child stopped using his controller nebulizer altogether.
- ☐ My child did not change this medication at all. He took it like the doctor said.



3. **Asthma/Allergy Controller Pill or Chewable Tablet or Sprinkles** - like Singulair

Did the doctor ask your child to take this medicine?



YES ☐ (answer below)

NO ☐ (skip to #4)



How did you change this medication in the past 3 months?

- ☐ My child took *MORE* pills/teaspoons when he took it.
- ☐ My child took the pill/liquid *MORE* times (more doses) during the day.
- ☐ My child skipped doses (e.g., skipped a whole day).
- ☐ My child stopped taking the medicine altogether.
- ☐ My child did not change this medication at all. He took it like the doctor said.



4. **Rescue Inhaler** – like albuterol, Proventil, Ventolin, Maxair

**Did the doctor ask your child to take this medicine?**

YES ☐ (answer below)

NO ☐ (skip to #5)



How did you change this medication in the past 3 months?

- ☐ My child took *MORE* puffs when he took it.
- ☐ My child used the inhaler *MORE* times (more doses) during the day.
- ☐ My child took *FEWER* puffs when he took it.
- ☐ My child skipped doses (e.g., morning, bedtime, skipped a whole day).
- ☐ My child stopped taking the medicine altogether.
- ☐ My child did not change this medication at all. He took it like the doctor said.



5. **Asthma Rescue Nebulizer** (breathing treatments of rescue medicine) –  
like Xoponex, albuterol, Atrovent

**Did the doctor ask your child to take this medicine?**

YES ☐ (answer below)

NO ☐ (skip to #6)



How did you change this medicine in the past 3 months?

- ☐ My child took *MORE MEDICINE* during a nebulizer treatment.
- ☐ My child used the nebulizer *MORE* times during the day.
- ☐ My child took *LESS MEDICINE* during a nebulizer treatment.
- ☐ My child skipped nebulizer treatments (e.g., morning, bedtime, skipped a whole day).
- ☐ My child stopped using his rescue nebulizer altogether.
- ☐ My child did not change this medication at all. He took it like the doctor said.

6. **Allergy Nose Spray** – like Flonase, Nasacort, Rhinocort, Nasonex

**Did the doctor ask your child to take this medicine?**

YES ☐ (answer below)

NO ☐ (skip to #7)



How did you change this medicine in the past 3 months?

- ☐ My child used *MORE* sprays when he took it.
- ☐ My child used the nose spray *MORE* times (more doses) during the day.
- ☐ My child used *FEWER* sprays when he took it.
- ☐ My child skipped doses (e.g., morning, bedtime, skipped a whole day).
- ☐ My child stopped taking the medicine altogether.
- ☐ My child did not change this medication at all. He took it like the doctor said.

7. **Allergy Pill or Liquid** – like Allegra, Claritin or Alavert (loratidine), Clarinex, Zyrtec (cetirizine)

Did the doctor ask your child to take this medicine?

YES ☐ (answer below)

NO ☐ (skip to bottom of this page) --

How did you change this medicine in the past 3 months?

- ☐ My child took *MORE* pills/teaspoons when he took it.
- ☐ My child took the pill/liquid *MORE* times (more doses) during the day.
- ☐ My child took *FEWER* pills/teaspoons when he took it.
- ☐ My child skipped doses (e.g., morning, bedtime, skipped a whole day).
- ☐ My child stopped taking the medicine altogether.
- ☐ My child did not change this medication at all. He took it like the doctor said.

Did you make **ANY CHANGES** to your child's asthma medicines in the **past 3 months**?

YES ☐ (go to NEXT PAGE)

NO ☐ (skip to PART 6)

---

**PART 4: Reasons for Changing Our Child's Asthma Medicine Routine**

---

Have you **INCREASED** your child's asthma medicine (more doses, more puffs, larger amount) over the past 3 months?

**YES**    ☐ (answer items below)

**NO** ☐ (skip to next page) →

↓ Families have different reasons for making changes or adjustments to their child's asthma medicine routine. Many possible reasons are listed below. For each item, mark whether it is "**True**" or "**False**" as a REASON WHY you and/or your child **INCREASED** your child's asthma medicine over the PAST 3 MONTHS. More than one reason can be marked as "True."

	<b>TRUE</b>	<b>FALSE</b>
The amount of a medicine the doctor told my child to take was <i>too little</i> .		
My child's asthma was getting in the way of her being able to exercise or play sports.		
My child's asthma seemed to flare up with every cold or virus.		
My child was becoming wheezy during normal/ daily physical activity (for example: walking, climbing stairs).		
My child's allergies seemed to be triggering my child's asthma.		
My child couldn't sleep through the night without asthma symptoms.		
My child was missing too many school days because of his asthma.		
My child was scared of wheezing.		
My child wanted to cut down his need to use his rescue inhaler so often.		
My child wanted to avoid taking antibiotics for her chest symptoms.		
We wanted to have better control over our child's asthma.		
We did <i>not</i> want to worry as much about our child's asthma, so we changed the medicine routine to make the medicine work better.		
We were tired of our child going to the Emergency Room or having to stay in the hospital because of his asthma.		
<b>Other (write your own):</b>		

Have you **DECREASED** your child's asthma medicine (fewer doses, less puffs, smaller amount) over the past 3 months?

YES ☐ (answer items below)

NO ☐ (skip to part 5) →

↓ For each item, mark whether it is "**True**" or "**False**" as a REASON WHY you and/or your child **DECREASED** your child's asthma medicine over the PAST 3 MONTHS. More than one reason can be marked as "True."

	TRUE	FALSE
The amount of a medicine the doctor told my child to take was <i>too much</i> .		
My child's asthma got better.		
The medicine did <i>not</i> seem to be working.		
My child was taking too many different medicines.		
We did not agree with the doctor's diagnosis of asthma or allergies.		
Carrying around the asthma medication supplies was too much hassle		
The medicine made my child feel or act different.		
Taking too much medicine was bad for my child.		
We wanted our child to use home remedies or other things that were <i>not</i> medicine to treat his asthma.		
The medicines cost too much money.		
My child got upset or threw tantrums and did not want to take the medicine.		
We wanted to find out what would happen to our child's asthma if he stopped taking a medicine.		
We were worried that the medicine would <i>not</i> work after some time if our child took it too long.		
Life was too busy and our child forgot the medicine too often to bother taking it at all anymore.		
We ran out of the medicine before we could get more.		
My child complained that the medicine tasted bad.		



For each one, mark whether it is “*True*” or “*False*” as a REASON WHY you and/or your child **DECREASED** your child’s asthma medicine routine over the PAST 3 MONTHS.

	TRUE	FALSE
We wanted to get rid of the side effects from the medicine.		
We wanted to make the medicines last longer, so we would not have to buy as much.		
My child did <i>not</i> want to take medicines during an activity (e.g., sleepovers, sports team practice).		
My child did <i>not</i> want his friends to know that he had to take asthma medicine.		
We did not like the way (e.g., having to use a spacer, inhaler; having to swallow a pill or liquid) our child had to take the medicine.		
We were worried that our child would become addicted to or dependent on the medicine if he took too much.		
It was too hard to keep track of all of my child’s medicines.		
We wanted to make our child’s medicine routine easier to follow or remember.		
Taking medicines got in the way of our family’s daily life too much.		
<b>Other (write your own):</b>		

---

**PART 5: HOW WE CHANGE OUR CHILD'S ASTHMA MEDICINE ROUTINE**

---

For each statement below, mark whether it is "*True*" or "*False*" as to HOW your family makes planned changes or adjustments to your child's asthma and/or allergy medication routine. Again, these changes are NOT the result of those your child's asthma action plan says or due to forgetting.

	TRUE	FALSE
We are careful when talking to the doctor about the changes we have made because we are not sure how the doctor will react.		
When we make changes in our child's asthma routine, we just see how it goes rather than closely monitor its effect.		
We tell the doctor <i>after</i> making medicine changes so that the doctor knows how it worked.		
We use peak flow readings as a way to know if our medicine changes are working.		
We do not always remember to tell the doctor the changes we have made in the medicine plan.		
We use our child's asthma problems as a way to know if our medication changes are working.		

## Appendix B. Asthma Management Self-Efficacy

### Parent Asthma Management Self-Efficacy

*Instructions:* The questions below are about how sure you are that you can do things to help your child's asthma. There are not right or wrong answers. This is not a test. Please circle the answer that is most true for you. If the answer doesn't make sense for you, please circle "8".

	Not at all sure	A little bit sure	Fairly sure	Quite sure	Completely Sure	Does not apply
1. How sure are you that you can get your child to take his/her medications?	1	2	3	4	5	8
2. How sure are you that you can use the medication correctly?	1	2	3	4	5	8
3. How sure are you that you can get your child to a doctor's appointment?	1	2	3	4	5	8
4. How sure are you that you can follow the directions for giving medications to your child?	1	2	3	4	5	8
5. How sure are you that you can help your child avoid things he/she is allergic to?	1	2	3	4	5	8
6. How sure are you that you can help your child prevent a serious breathing problem?	1	2	3	4	5	8
7. How sure are you that you can have inhalers with you if your child has a serious breathing problem?	1	2	3	4	5	8
8. How sure are you that you can control a serious breathing problem at home rather than take your child to the ER?	1	2	3	4	5	8
9. How sure are you that you can keep the asthma from getting worse if your child starts to wheeze or cough?	1	2	3	4	5	8
10. How sure are you that you can help your child stay calm during a serious breathing problem?	1	2	3	4	5	8
11. How sure are you that you would know which medications to use when your child is having a serious breathing problem?	1	2	3	4	5	8
12. How sure are you that you know when your child's breathing problem can be controlled at home?	1	2	3	4	5	8
13. How sure are you that you know when to take your child to the emergency room?	1	2	3	4	5	8

## Appendix C. Functional Severity Index

**Functional Severity Index**  
**Asthma Symptom Assessment Form**

1. Some children only have episodes of asthma from time to time and feel well between these episodes. Other children, however, may feel wheezy or tight in the chest on most days, but also suffer from more severe episodes of asthma. In the last month, how often did your child have episodes of wheezing?

\_\_\_\_\_ Daily      \_\_\_\_\_ A few times a week      \_\_\_\_\_ A few times a month  
\_\_\_\_\_ Once a month      \_\_\_\_\_ Never      \_\_\_\_\_ Don't Know

2. In the last month, how often did your child wake at night with a cough or wheezing?

\_\_\_\_\_ Nightly      \_\_\_\_\_ A few nights a week      \_\_\_\_\_ Less than one night/week  
\_\_\_\_\_ Only with episodes      \_\_\_\_\_ Never      \_\_\_\_\_ Don't Know

3. In the last month, how often was your child's wheezing troublesome first thing in the morning?

\_\_\_\_\_ Daily      \_\_\_\_\_ A few mornings a week      \_\_\_\_\_ Less than one morning/week  
\_\_\_\_\_ Only with episodes      \_\_\_\_\_ Never      \_\_\_\_\_ Don't Know

4. In the last month, has your child had an attack that has been severe enough to limit speech to only one or two words at a time between breaths?

\_\_\_\_\_ Yes      \_\_\_\_\_ No      \_\_\_\_\_ Don't Know

5. In the last month, how often were your child's activities (other than sports) affected or limited by cough or wheezing or shortness of breath?

\_\_\_\_\_ Daily      \_\_\_\_\_ A few times a week      \_\_\_\_\_ A few times a month  
\_\_\_\_\_ Less than once a month      \_\_\_\_\_ Never      \_\_\_\_\_ Don't Know

6. In the last month, how often were your child's sports activities (at school or after school) limited or affected by cough or wheezing or shortness of breath?

\_\_\_\_\_ Daily      \_\_\_\_\_ A few times a week      \_\_\_\_\_ A few times a month  
\_\_\_\_\_ Less than once a month      \_\_\_\_\_ Never      \_\_\_\_\_ Don't Know

7. How many days has your child been in the hospital for asthma:  
in the past month? \_\_\_\_\_ past year? \_\_\_\_\_

8. How many times has your child been in the emergency room for asthma:  
in the past month? \_\_\_\_\_ past year? \_\_\_\_\_

9. How many time has your child seen a doctor for asthma:  
in the past month? \_\_\_\_\_ past year? \_\_\_\_\_
10. How many days of school has your child missed due to asthma:  
in the past month? \_\_\_\_\_ past year? \_\_\_\_\_
11. What medication has your child taken for asthma in the past month? (list)
12. Has your child had any oral steroids (e.g., prednisone burst, prelone):  
in the past year? \_\_\_\_\_ Yes \_\_\_\_\_ No  
ever? \_\_\_\_\_ Yes \_\_\_\_\_ No
13. How many days in the past month has your child had any symptoms of asthma? \_\_\_\_\_

*Adapted from: Rosier, Bishop, Nolan, Robertson, Carlin, & Phelan (1994); Fritz, McQuaid, Spirito, & Klein (1996).*

## Appendix D. Patient Information Form



SUBJECT # \_\_\_\_\_

TODAY'S DATE: \_\_\_\_\_

## PATIENT INFORMATION FORM

*Note: This form should be completed by PARENT, with the help of the patient. Please answer the following questions as well as you can. If you have any problems, please ask the researcher for some help.*

### CHILD INFORMATION:

AGE: \_\_\_\_\_ GRADE: \_\_\_\_\_

SEX (circle):    Male    Female

RACE (circle):    Caucasian            African-American            Asian-American            Hispanic-American

Other: \_\_\_\_\_

**1. Has your child ever been diagnosed with asthma prior to this appointment?**

\_\_\_\_\_ No            \_\_\_\_\_ Yes (At what age? \_\_\_\_\_)

If **YES**, did your child previously receive a WRITTEN asthma action plan on what to do each day for your child's asthma care and how to respond to asthma episodes? This plan may have included information on what to do in a green zone, yellow zone, and red zone.

\_\_\_\_\_ No            \_\_\_\_\_ Yes

**2. Does your child have any relatives (family members) with asthma?**

\_\_\_\_\_ No            \_\_\_\_\_ Yes

If YES, list ALL of them (mother, grandfather, cousin, etc.): \_\_\_\_\_

\_\_\_\_\_

**3. What asthma and allergy medicines are you *currently* giving your child?**

<i>Name of Medicine</i>	<b><u>Dose</u> (number of puffs, pills, teaspoons)</b>	<b><u>Schedule</u> (morning, night, twice a day)</b>

**4. Does your child have any illnesses other than asthma?**

\_\_\_\_\_ No            \_\_\_\_\_ Yes (Please List: \_\_\_\_\_)

**5. Has your child received any kind of special education services for learning problems?**

\_\_\_\_\_ No            \_\_\_\_\_ Yes (In what grades? \_\_\_\_\_)

6. Has your child ever been seen by a doctor or psychologist for behavioral problems?

\_\_\_\_\_ No \_\_\_\_\_ Yes (For what diagnosis/ problems? \_\_\_\_\_)  
\_\_\_\_\_

7. What type of health insurance does your child have? Please list all.

\_\_\_\_\_  
\_\_\_\_\_

**FAMILY INFORMATION:**

WHAT IS YOUR RELATIONSHIP TO THE CHILD (for example: mother, grandparent)?

\_\_\_\_\_ YOUR AGE: \_\_\_\_\_

1. Please make a check in front of each family member that is *CURRENTLY* living in your child's home.

_____ Biological Mother	_____ Biological Father
_____ Adoptive or Step-Mother	_____ Adoptive or Step-Father
_____ Brother (How many? _____)	_____ Sister (How many? _____)
_____ Grandparent (How many? _____)	
_____ Other (list by relationship to child) _____	

2. Please make a check in front of your marital status.

_____ Never Been Married / Single	_____ Divorced / Single
_____ Married to other biological parent	_____ Remarried to step-parent
_____ Living with boyfriend / girlfriend	_____ Widowed (other biological parent is deceased)

**For the rest of the questions on this page, please list/describe those people (typically, the parents) that PROVIDE FOR THE HOUSEHOLD (help to pay bills, buy food, buy clothes, etc.).**

- |   |   |  |
|---|---|--|
| 1 | = | 6th grade or less  |
| 2 | = | 7th, 8th, or 9th grade   |
| 3 | = | Some high school (10th or 11th grade)  |
| 4 | = | Graduate from high school  |
| 5 | = | Some college (at least 1 year) or specialized training (example: Vocational) |
| 6 | = | Bachelor's degree, graduated from a 4-year college (UF, FSU, USF, etc.)      |
| 7 | = | Master's degree, doctoral degree   |

3. Using the above scale in the box, please show the *highest* level of education *completed* by the people who PROVIDE for the CHILD (help pay bills, buy food, buy clothes). If the person listed is NOT the mother or father of the child, please write who this person is (for example: step-parent, grandparent) next to it.

Mother = \_\_\_\_\_

Father = \_\_\_\_\_

4. Please provide a job title & description for the persons listed in Question # 3.

Mother (or other):

\_\_\_\_\_

Father (or other):

\_\_\_\_\_

5. Please check your total, annual family income level:

- \_\_\_\_\_ Less than \$10,000  
\_\_\_\_\_ \$10,000 - \$19,999  
\_\_\_\_\_ \$20,000 - \$29,999  
\_\_\_\_\_ \$30,000 - \$39,999  
\_\_\_\_\_ \$40,000 - \$49,999  
\_\_\_\_\_ \$50,000 - \$59,999  
\_\_\_\_\_ \$60,000 - \$69,999  
\_\_\_\_\_ \$70,000 and greater